

Open Research Online

The Open University's repository of research publications and other research outputs

Keeping connected and staying well: the role of technology in supporting people with learning disabilities during the coronavirus pandemic.

Other

How to cite:

Seale, Jane (2020). Keeping connected and staying well: the role of technology in supporting people with learning disabilities during the coronavirus pandemic. The Open University.

For guidance on citations see [FAQs](#).

© 2020 Open University



<https://creativecommons.org/licenses/by-nc-nd/4.0/>

Version: Version of Record

Link(s) to article on publisher's website:

<https://www.housinglin.org.uk/Topics/type/Keeping-Well-and-Staying-Connected/>

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's data [policy](#) on reuse of materials please consult the policies page.

oro.open.ac.uk

KEEPING CONNECTED AND STAYING WELL



THE ROLE OF TECHNOLOGY IN SUPPORTING PEOPLE WITH LEARNING DISABILITIES DURING THE CORONAVIRUS PANDEMIC

This report has been written by Jane Seale with contributions from Shaun Picken, Lorna Rouse, Liz Tilley, Louise Wallace, and Jan Walmsley.

To cite this report: Jane Seale (2020) Keeping connected and staying well: the role of technology in supporting people with learning disabilities during the coronavirus pandemic, Milton Keynes, The Open University.

CONTENTS

EXECUTIVE SUMMARY	3
GLOSSARY OF TERMS	5
INTRODUCTION	6
THE RESEARCH PROJECT	8
KEY FINDINGS	12
CONCLUSIONS	45
RECOMMENDATIONS	46
ACKNOWLEDGEMENTS	48
REFERENCES	49

EXECUTIVE SUMMARY

During the pandemic we have seen how many people, faced with the prospect of working at home, not being able to meet up with friends or family, or unable to go shopping for food or other essentials have turned to technology to help them achieve these tasks remotely. It has not been clear however, what, if any, support people with learning disabilities have received to enable them to use technology to keep connected and stay well during the pandemic. In order to find out, we conducted an online survey of supporters and also interviewed supporters and people with learning disabilities. We received 106 survey responses and interviewed 44 supporters and 20 people with learning disabilities. Our analysis of the results revealed 8 main findings.

Finding 1: Supporters are blending technological means of support with non-technological means.

Finding 2: As part of a blended approach to support, supporters are using a wide range of technologies. The exact 'mix' of technologies is influenced by a range of factors.

Finding 3: The main reasons supporters gave for using technology with people with learning disabilities during the pandemic were to contribute to good mental health and/or well-being; to help combat loneliness and a sense of isolation; to help overcome boredom through lack of activity and to provide information about the coronavirus and staying safe.

Finding 4: The practices that remote supporters engage in when using technologies to support people with learning disabilities can be characterised as speedy, evolving, creative and fearless.

Finding 5: One of the most significant factors that enables people with learning disabilities to use and benefit from technologies during lockdown is support from someone living with them.

Finding 6: The most significant barriers to enabling people with learning disabilities to use and benefit from technologies during lockdown are The Digital Divide and Lack of In-Home Support

Finding 7: Using technology to support people with learning disabilities during lockdown has had a positive impact on their mental health, well-being, sense of belonging and connectedness.

Finding 8: Using technologies to support people with learning disabilities during lockdown has highlighted the technological capabilities of people with learning disabilities and the potential of new support practices.

The experience of using technology to support people with learning disabilities during the pandemic has led many supporters to conclude that it would be beneficial to continue these practices beyond the pandemic and indeed to develop them further. For this to happen and to be successful however, attention needs to be paid to the significant barriers that this research has identified.

EDUCATION, HEALTH AND SOCIAL CARE PROVIDERS AND COMMISSIONERS

1. Collect detailed information about what technologies the people with learning disabilities that they support currently do and do not have access to and what they would like to have access to and be able to use. Create a detailed picture of what the digital divide looks like in their context.
2. Plan how to fund, set-up and distribute technologies to those people with learning disabilities who do not have access to technologies. But don't provide access to new technologies without also ensuring that the person with a learning disability and their in-home supporters know how to use it and can afford to use in the case of mobile phones and data.
3. Develop and embed in the practices and cultures of those organisations that deliver education, health, and social care innovative capacity-building programmes for both people with learning disabilities and their supporters (including family members) so that they can confidently use technology.
4. Review, and where necessary revise the policies and practices of those organisations that deliver education, health, and social care to ensure that they do not place unnecessary barriers in the way of enabling access to technology and effective in-home support. The experiences of those who have been providing remote support (including family members) can usefully inform this review process.

SELF-ADVOCACY GROUPS, ADVOCACY GROUPS, LEARNING DISABILITY CHARITIES, FAMILIES, DAY SERVICE PROVIDERS, TEACHERS, HEALTH, AND SOCIAL CARE PROFESSIONALS

5. Collect, curate and share examples of how supporters have used technology to support people with learning disabilities during this pandemic in order that others may be able to learn from them and adopt or adapt when they develop their own support practices. As part of this initiative, it is important that family members that have been anxious about using technology are connected to family members and other supporters who have overcome these anxieties and can share the successful strategies they have employed.
6. Set up and maintain co-operative, collaborative partnerships between those who provide in-house support (e.g. care homes, supported living; family members) and those who have the experience and expertise to provide remote support (e.g. self-advocacy groups, day services).

ALL THOSE WHO HAVE A ROLE IN SUPPORTING PEOPLE WITH LEARNING DISABILITIES:

7. Believe, that with the right support, people with learning disabilities have the capacity to learn to use technology. There are many examples in this report that evidence this capacity.
8. Believe that people with learning disabilities have the right to both access technology and the support to enable them to access that technology.

GLOSSARY OF TERMS

LEARNING DISABILITY



For the purposes of this report we are using the term 'learning disabilities' to refer to some form of difficulty with experiencing and acquiring new information, which typically starts in childhood and impacts on ability understand new or complex information, to learn new skills and to cope independently (Department of Health, 2001).

SELF-ADVOCACY ORGANISATION



Self-advocacy means knowing your rights and responsibilities, speaking-up for your rights, and being able to make choices and decisions that affect your life. In the context of this report, we will use the term 'self-advocacy organisation' to refer to any group or organisation that supports people with learning disabilities to develop the capacity and confidence to self-advocate.

SUPPORT WORKER / STAFF MEMBER



In the context of this report we have used the terms 'support worker' and 'staff member' to refer to someone who is not a self-advocate but is employed by a self-advocacy organisation to support the organisation's activities. This includes: supporting members to self-advocate and supporting project management and the day to day running of the organisation.

TECHNOLOGY



We are using a broad definition of technology in this report in order to capture all possible kinds of support that might be provided to people with learning disabilities during the COVID-19 pandemic. For example, technologies that support communication with others, access to information or services or engagement in leisure, educational and therapeutic activities. Typical examples of technology include: mobile and Smart phones; tablets, personal computers and laptops; communication apps such as Zoom, Skype and WhatsApp; the Internet and apps available online such as YouTube; social media apps such as Facebook and Twitter; games consoles; MP3 players and other devices that play stored music.



INTRODUCTION

The impact of the pandemic on people with learning disabilities

The focus of this research report is whether and how technologies have been used to support people with learning disabilities living in the UK during the coronavirus pandemic. The report focuses particularly on the first six months of the pandemic, when, during a period of national 'lock-down' people with learning disabilities, like everyone else, were self-isolating or shielding and thus disconnected from their usual support systems, regular social interactions and activities.

There has been much discussion in the UK media and research communities about how being isolated during the pandemic has affected the nation's health and well-being. This is particularly true for people with learning disabilities.

Prior to the pandemic, people with learning disabilities already experienced significant health inequalities including avoidable, premature death. Furthermore, given that respiratory conditions were the most common cause of death among people with learning disabilities prior to the pandemic, there was a strong indication that they may be at greater risk of dying from COVID-19 (Lodge, 2020). This, combined with arguments regarding the indifference of the health and social care system to the health of people with learning disabilities has led to close scrutiny of national statistics produced by ONS, The Care Quality Commission and LeDeR relating to the deaths of people with learning disabilities. This reveals that people with learning disabilities are at greater risk of dying from COVID-19 (Hatton, 2020).

The impact of social distancing and shielding is also reported to be having an impact on the mental health of people with learning disabilities. One reason for this, is the sudden change of routine. Many people with learning disabilities benefit from and value opportunities to engage in regular activities such as volunteering or working, attending day services, attending self-advocacy group meetings, and socialising with friends and family. The loss of these opportunities has been devastating:

“A lot of people’s worlds came to an end”

(Richard Keagan-Bull from Lambeth Learning Disability Assembly, speaking at an LDE Webinar on June 24th, 2020)

Other factors that are contributing to poor mental health for people with learning disabilities are the reduction or removal of support, increased social isolation and uncertainty about how long the measures will last (Scottish Commission for Learning Disability, 2020; Gulati et al. 2020).

THE POTENTIAL ROLE OF TECHNOLOGY IN MEDIATING THE NEGATIVE EFFECTS OF THE PANDEMIC

During the pandemic we have seen how many people, faced with the prospect of working at home, not being able to meet up with friends or family, or unable to go shopping for food or other essentials have turned to technology to help them achieve these tasks remotely. For example, video conferencing tools such as Skype and Zoom have rapidly become ubiquitous as tools for enabling remote meetings; access to the Internet has become vital in order to shop online, order repeat prescriptions and gain access to information on how to 'stay safe'. Furthermore, we have seen how ownership of modern Smartphones has become necessary in order to use government recommended Apps such as 'NHS Test and Trace'.

On the face of it, it would seem reasonable to assume that people with learning disabilities would be turning to these technologies as well. Indeed research conducted prior to the pandemic, has shown that many people with learning disabilities are highly motivated to use technology, are very competent technology users when given the opportunity to access and use technology, and derive a great deal of pleasure and benefit from using technology for a variety of purposes (Seale, Choksi & Spencer, 2019).

However, research conducted prior to the pandemic has also shown that whilst many people with learning disabilities are highly motivated to use technology, they are often unable to effectively or meaningfully do so (Agren, Kjellberg & Hemmingson, 2019; Lussier-Desrochers et al. 2017). The reasons for this are varied and include lack of access to technology and not knowing how to use technology. However, several researchers have argued that a major reason that people with learning disabilities are excluded from the benefits that using technology can offer them is that supporters (e.g. parents, carers and other professionals) are often unable or unwilling to facilitate access and support sustained use of technology (Seale, 2014; Sorbring, Molin & Löfgren-Mårtenson, 2017). This is why it is important to examine whether and how people with learning disabilities are being supported to use technologies during the coronavirus pandemic. Therefore, the research questions that will be the focus of this report are:

RQ 1 How is technology being used to support people with learning disabilities during the pandemic in the UK?

RQ 2 What factors have helped or hindered the use of technology to support people with disabilities during the pandemic?

RQ 3 What lessons can be learnt about the use of technology to support people with learning disabilities during the pandemic that can inform post-pandemic practices?

THE RESEARCH PROJECT



RESEARCH DESIGN

The study reported here was part of a larger project which was funded by the Open University as part of its COVID-19 research initiative. This larger project had two strands:

1. Exploring the role of self-advocacy groups in supporting the health and wellbeing of adults with learning disabilities during the pandemic (led by Liz Tilley and Louise Wallace).
2. Identifying creative practice involving technologies that self-advocates, supporters and others are adopting during the pandemic to enable people with learning disabilities to connect with others and lessen the feelings of isolation (led by Jane Seale).

In the first strand of the project we wanted to explore the ways in which self-advocacy groups mobilised during lockdown and in the recovery period to support their members in different ways.

Members of self-advocacy groups (people with learning disabilities and self-advocacy facilitators or co-coordinators) were interviewed in order to ascertain how self-advocacy groups are operating during the pandemic in order to respond to the needs of their members, with a particular focus on how they are supporting people's wellbeing. As many people with learning disabilities fall into 'shielded' groups, we anticipated that self-advocacy organisations would most likely be delivering at least some of their services remotely for at least the next 12-18 months, necessitating the use of technology. Therefore, although the main focus of the interviews was well-being, we also included some questions about their use of technology. Answers to these questions are integrated with data obtained from the second

strand of the project. We have produced a separate report called 'Filling in the Gaps' which presents the results of this first strand of research (Rouse et al. 2020).

The aim of the second strand of the project was to identify the creative practices that 'supporters' were adopting in order to use technologies to enable people with learning disabilities connect with others, access services or lessen feelings of isolation during the lock-down. We were particularly interested in learning about:

- How people with learning disabilities and their 'supporters' have solved problems around access to technology as well as levels of confidence and ability to use technologies
- Where the 'sticking points' are in terms of implementing these creative practices and what the critical variables are (e.g. setting, level of care, nature of relationship with supporters, money, risk perceptions).

By identifying these practices and variables it is anticipated that we can contribute to the development of support practices that are more sustainable longer term. In this report, data from both strands is used to examine the role of technology in supporting people with learning disabilities during the coronavirus pandemic.

DATA COLLECTION METHODS

In order to answer the research questions, two data collection methods were employed: an online survey and semi-structured interviews.

SURVEY

An online survey was designed with seven questions that sought to find out from supporters: what technologies they were using to support people with learning disabilities during the lock-down; The reasons for using the technology; perceptions regarding how successful the experience of using technology has been; the factors that have helped their use of technology and the factors that have made using technology difficult.

The survey was created using the JISC Online Survey and the link to the survey was disseminated via Twitter and email lists. The survey opened on 22nd June 2020 and closed on 31 July 2020. There were 106 valid responses to the survey.

SEMI-STRUCTURED INTERVIEW

Participants in both strands of the overarching project were invited to take part in the interview. For strand one, members of self-advocacy groups known to the researchers through their networks were contacted directly via email and invited to participate. For strand two, supporters who had responded to the online questionnaire were invited to volunteer to take part in a follow up interview.

For the interviews with members of self-advocacy organisations in strand one of the project, the interview questions mirrored those asked in the online survey and sought to find out about what technologies were being used, the different purposes that technologies were being used for, the impact of this use on people with learning disabilities, perceptions regarding whether the use of technology had been successful and the factors that contributed to the success or failure of technology use. For the interviews with 'supporters' in strand two of the project, the interview explored technology use with people with learning disabilities before and during lock-down as well as visions and advice for technology use post lock-down.

The interviews were conducted remotely using a variety of technologies including mobile phone, WhatsApp, Skype, and Microsoft Teams. The interviews were audio-recorded and transcribed. The combined duration of the interviews was 2329 mins and 30 seconds. The shortest interview was 32 minutes and 18 seconds and the longest was 112 minutes and 4 seconds. The average length of an interview was 58 mins and 23 seconds.

From strand one, 11 self-advocacy organisations agreed to be interviewed. These interviews were mainly group interviews. From strand two, 27 supporters agreed to be interviewed. These were mainly individual interviews. On one occasion one parent was interviewed with their adult child, a person with a learning disability. The interviews took place between 3rd July and 3rd September 2020.

DATA ANALYSIS

For the survey data, descriptive statistics have been calculated for answers to the closed questions and a thematic analysis has been conducted on answers to the open questions. For the interview data all the transcripts were read by four members of the research team. Each member identified potential core themes and narratives across all the interviews and then shared these in a follow-up team meeting and set of common themes and narratives were then agreed.

PARTICIPANTS

ONLINE SURVEY PARTICIPANTS

The 106 respondents of the online survey were asked to indicate their role or relationship with a person with a learning disability. In recognition that people can have more than one role (e.g. parent of a person with a learning disability and an employee of a self-advocacy organisation) respondents were able to indicate all the roles that applied to them. This revealed that the largest group of respondents were employees or volunteers of a self-advocacy organisation, learning disability charity or similar; health professionals and parents or family members (See Table 1).

Table 1: Variety of roles occupied by online survey respondents

Role	Number of responses	Percentage
Employee or volunteer of a self-advocacy organisation, learning disability charity, or similar	35	33%
Health professional	32	30.2%
Parent or family member	20	18.9%
Paid carer or support worker	13	12.3%
Education professional	6	5.7%
Friend or colleague	5	4.7%
Other	3	2.8%
Social Worker	1	0.9%
Person with a learning disability	1	0.9%

INTERVIEWEES

For the strand one interviews with the 11 self-advocacy organisations, 38 people took part in the interviews: 22 self-advocates (people with learning disabilities) and 16 self-advocacy facilitators or co-ordinators. All of the self-advocacy groups were based in England and were located in both the North and South of England. For the strand two interviews conducted with the 27 'supporters', the largest groups represented were parents, day service providers, advocacy organisations and support organisations (See Table 2). The majority of interviewees were based in England and Scotland. One interviewee was located in Wales and one in the Republic of Ireland.

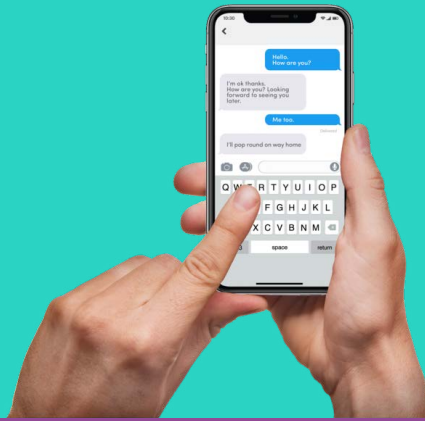
Table 2: Spread of roles for the 27 'support worker' interviews

Role	Frequency	Code
Parent	3	PAR
Service provider- day services e.g. art and other activities	4	SP
Advocacy organisation	4	AD
Support organisation	4	SUPP
Self-advocacy organisation	2	SA
Sibling	2	SIB
Education professional	3	EP
Health professional	2	HCP
Social care professional	1	SCP
Learning disability charity	1	CHAR
Other	1	OTHER

When presenting quotes from participants in the next section of the report we will identify them with a code that indicates their role (e.g. PAR1, PAR2, SP3, SP4 etc.). On occasion, we will edit quotes for length or sense, but our over-riding aim is to give voice to our participants.

ETHICS

Ethical approval to conduct the study was obtained from the Human Research Ethics Committee of the Open University (HREC/3604/Seale). Key ethical issues addressed in the protocol related to informed consent, anonymity and safeguarding. Easy read versions of the information sheets and consent forms were made available to participants with learning disabilities and where appropriate support workers facilitated the processing of the information and articulation of consent.



KEY FINDINGS

Our analysis of the results revealed 8 main findings.

Finding 1: Supporters are blending technological means of support with non-technological means.

Finding 2: As part of a blended approach to support, supporters are using a wide range of technologies. The exact 'mix' of technologies is influenced by a range of factors.

Finding 3: The main reasons supporters gave for using technology with people with learning disabilities during the pandemic were to contribute to good mental health and/or well-being; to help combat loneliness and a sense of isolation; to help overcome boredom through lack of activity and to provide information about the coronavirus and staying safe.

Finding 4: The practices that remote supporters engage in when using technologies to support people with learning disabilities can be characterised as speedy, evolving, creative and fearless.

Finding 5: One of the most significant factors that enables people with learning disabilities to use and benefit from technologies during lockdown is support from someone living with them.

Finding 6: The most significant barriers to enabling people with learning disabilities to use and benefit from technologies during lockdown are The Digital Divide and Lack of In-Home Support

Finding 7: Using technology to support people with learning disabilities during lockdown has had a positive impact on their mental health, well-being, sense of belonging and connectedness.

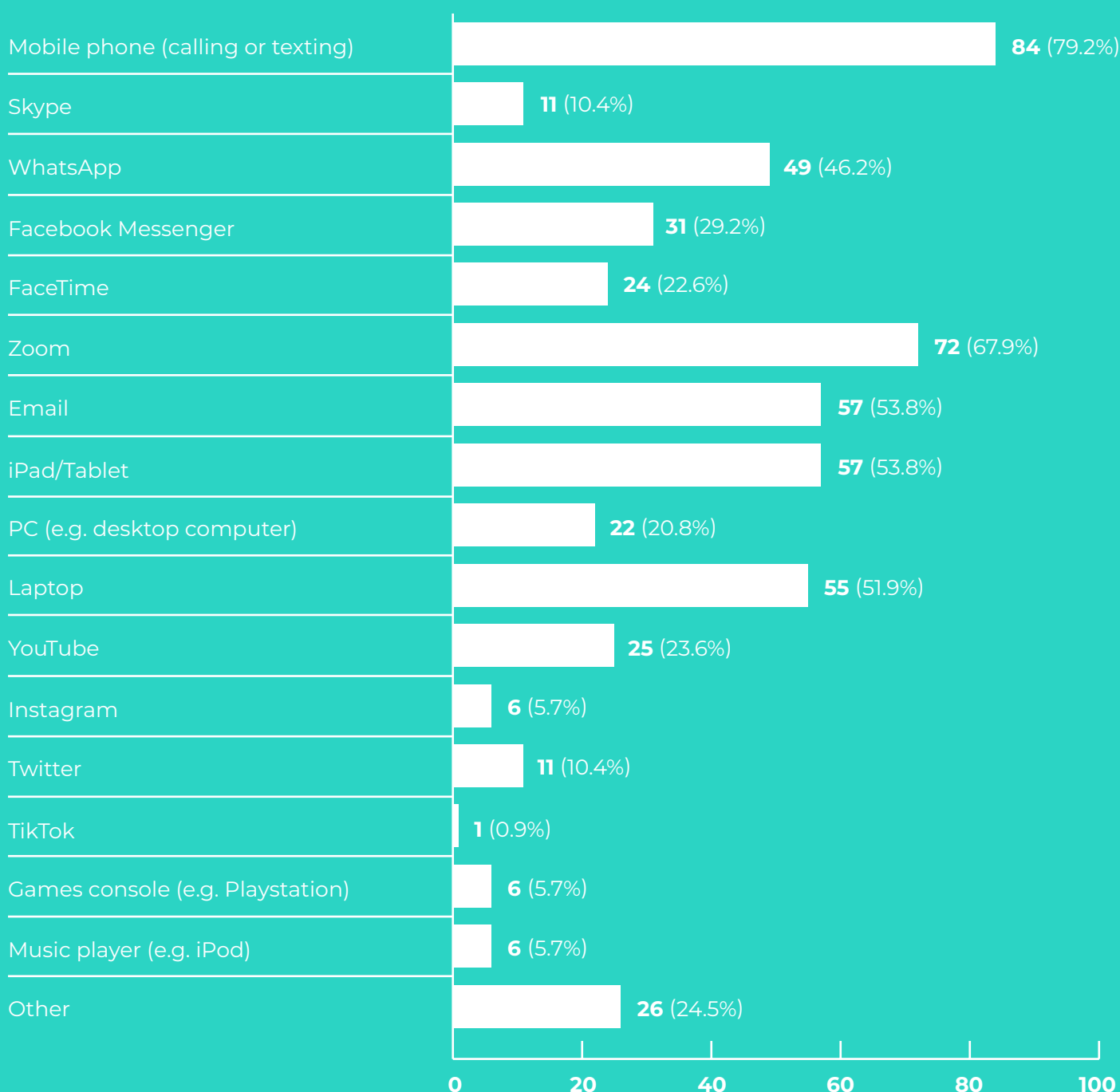
Finding 8: Using technologies to support people with learning disabilities during lockdown has highlighted the technological capabilities of people with learning disabilities and the potential of new support practices.

We will now illustrate each finding in more detail.

FINDING 1: SUPPORTERS ARE BLENDING TECHNOLOGICAL MEANS OF SUPPORT WITH NON-TECHNOLOGICAL MEANS.

Results from the survey indicated that the most common technology that was used by or with people with learning disabilities was the mobile phone, followed by Zoom, email, tablets and WhatsApp (See Figure 1). For those respondents who ticked the 'other' option, the most common examples they shared were applications that their employers (e.g. NHS) required them to use, typically, secure video-conferencing software (e.g. Pexip, BlueJeans, Microsoft Teams). Some of these respondents expressed frustration at how these and other restrictions put in place by their employer made it difficult to easily connect with the people they were trying to support.

Figure 1: The range of technologies that respondents indicate using to support a person with a learning disability during lockdown.



Multi answer: Percentage of respondents who selected each answer option (e.g. 100% would represent that all this question's respondents chose that option)

Experiences shared by interviewees revealed that when the lock-down was first announced in March the first thing that many supporters did (particularly those working for day services, support services, self-advocacy and advocacy groups) was attempt to reach all of their members by mobile phone to check how they were and to assess what support they needed. Most reported that they were not able to reach all of their members, and that this concerned them greatly. The main reason offered for this was that some people with learning disabilities that they supported, particularly those who lived with elderly parents or who were living independently, did not have a mobile phone or if they did they were not facilitated to answer the phone themselves. We will come back to this issue later on the report when we talk about the Digital Divide (See page 32).

The use of the mobile phone persisted throughout the pandemic and some organisations even received funding to phone 'members' as part of regular 'welfare-checks'. As the pandemic continued, supporters often introduced other technologies into their repertoire. In addition, many of these organisations blended their technological approach with more traditional methods of communication such as posting or delivering in person printed newsletters, activity packs and COVID-19 information resources. As one self-advocacy group put it: "digital is one response. It's part of a whole" (See our separate report 'Filling in the Gaps' for more detail). This blending of the technological and the non-technological was influenced, for the most part, by an understanding that not all the people with learning disabilities that they support had technologies and therefore needed to receive support in alternative ways:

“ It's been challenging just because everybody, people had such different things that they preferred. So, some people were happy with Zoom, some people were on WhatsApp, but didn't want Zoom, some people were on Facebook, some people didn't have anything. (SA5) ”



FINDING 2: AS PART OF A BLENDED APPROACH TO SUPPORT, SUPPORTERS ARE USING A WIDE RANGE OF TECHNOLOGIES. THE EXACT 'MIX' OF TECHNOLOGIES IS INFLUENCED BY A RANGE OF FACTORS

As part of a blended approach to support, supporters are using a wide range of technologies. The exact 'mix' of these technologies is influenced by three main factors:

- What technology the supporter has access to and was familiar with.
- What technology people with learning disabilities has access to and was familiar with
- Increasing understanding of the affordances of different technologies

The instinct for some supporters was to initially opt to use technologies that they were familiar with or that were part of standard practice in their organisation prior to lockdown. For example, if the organisation had a website or a Facebook page, they had immediately sought to use these as a means of support.

“ Before lockdown [...] I had a Facebook group, just to showcase what we do, promote the business very simply. when lockdown happened, my first thought was how can I continue to provide a service. How can I continue to serve them? So let's get on that - and the thing is if you have something there you can then direct people there. So let's get on there and see - so we got on [...] I know Facebook is easy to get onto, go live on, the first week we'd finished on the 19th, the next week we went online [...] so what we do is we get on Facebook live, all you have to be able to access is Facebook, get on your Facebook and go on to the private members group, so it's still a paying members group at this time, and they click onto that and we'll be on there doing a live session. (SP4) ”

As the pandemic continued some of these supporters did not expand on their repertoire. However, some supporters did begin to use a wider range of technologies. A common experience they shared with us is how during telephone 'welfare checks' some people with learning disabilities expressed a preference for alternative forms of communication e.g. Facebook or WhatsApp and that this would influence them to expand their repertoire.

“ What we started to do, we thought about how we could contact people. So initially, I rang up everybody. In total there were 38 people across the three groups. So I rang up everybody and asked them if they would like me to ring them on a regular basis or if they wanted me to write to them. So I asked them, what they would want. A few of them said: could we not have chats via WhatsApp. They wanted to see each other as well. So those who wanted me to, I still do, I ring around every week. Those who didn't, we started a WhatsApp group. (AD2) ”

For many supporters, the mix of technologies that they used was influenced by their growing familiarity with them. As they used technologies more regularly, they developed a stronger understanding of what the strengths and weaknesses of each technology were, and therefore the circumstances in which one technology might be chosen in preference to another. This is best illustrated in relation to the choice many supporters made to use Zoom. Reasons given included:

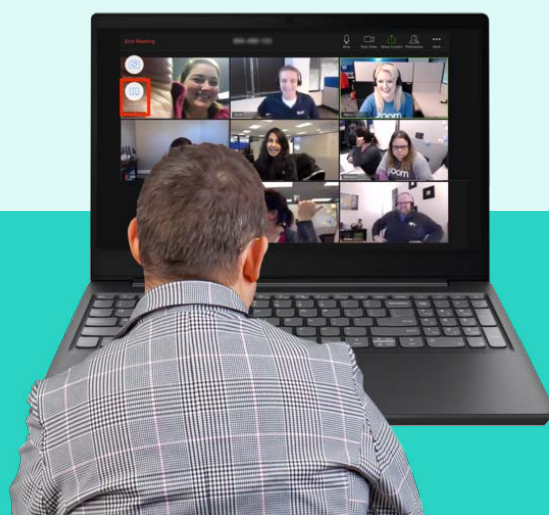
- People like to see the faces of the people they are talking to (better than the phone)
- It is easy to understand how to use
- It does not cut out as much as other video conferencing apps
- There is a free version
- All you need is the link- you can just send the link
- There is no need to be able to read
- You can have more people in a meeting (compared to Facebook Messenger)

Many supporters also developed an acute understanding of how using Zoom compared to using Microsoft Teams:

“ I’ll tell you something about Zoom though, if you’re in a big group. Say for instance you’re in a big group, like what I do on a Thursday [...] and also on a Wednesday when I do the[...] , if somebody’s saying something and there’s a group and there’s a lot of people in the group, you can actually put yourself on mute. But you can’t do that on other ones, but you can actually do it on Zoom. **(SA10)** ”

“ I think that some of the issues as well about working in an environment like this is, so we for example [...] we used to have our, we used Teams initially for our work stuff. But the trouble with Teams is you only get to see the people; you only get to see four people and it will change if someone talks. So [...] was getting left out a lot, because unless you talk you don’t get on screen and no one even knows you’re there. **(SA1)** ”

Whilst acknowledging the strengths of Zoom, many supporters were aware that there were aspects of its use that were difficult for people with learning disabilities. For example, in the early days of Zoom use, the need to type in a room id and password was problematic, as was having to wait to be let into the meeting room and not understanding the purpose of the mute button.



FINDING 3: THE MAIN REASONS SUPPORTERS GAVE FOR USING TECHNOLOGY WITH PEOPLE WITH LEARNING DISABILITIES DURING THE PANDEMIC WERE TO CONTRIBUTE TO GOOD MENTAL HEALTH AND/OR WELL-BEING; TO HELP COMBAT LONELINESS AND A SENSE OF ISOLATION; TO HELP OVERCOME BOREDOM THROUGH LACK OF ACTIVITY AND TO PROVIDE INFORMATION ABOUT THE CORONAVIRUS AND STAYING SAFE.

Supporters were motivated to use technologies to support people with learning disabilities because they were concerned that a combination of a loss of routine and being disconnected from friends and family as they shielded or self-isolated would result in them feeling lonely and/or bored which in turn would have a negative effect on their mental health and well-being. Whilst many people with learning disabilities understood that the sudden change to their lives was due to a virus and that they had to 'stay safe'; others did not understand and could not make sense of their new lives:

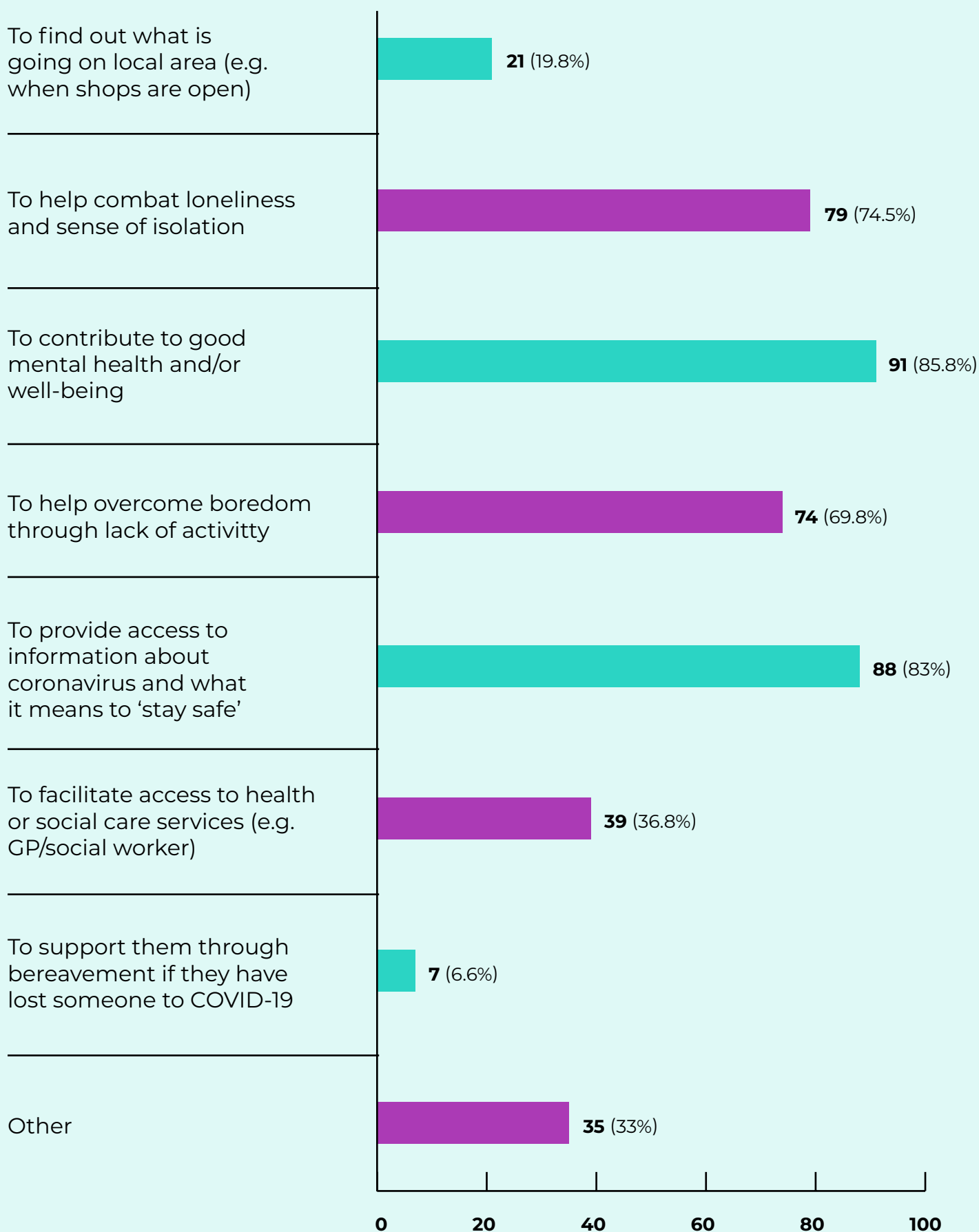
“ The students feel they are being punished. [...] Because it was a complete lifestyle change. I have got one student who absolutely loves going to the cinema with his dad and going out with his carer. He does things on a daily basis. It's very important that when he is in college, that he is accessing the community [...]. He is extremely social. It wasn't just that he wasn't going to college. He wasn't seeing anyone. His parents are currently shielding until August, so all he can do is see his parents, he can't go out, he can't go to the shops he can't do anything. And that was the same for all the students. I can think of at least 4 out of the group of 8 students who have got SLD or PMLD who thought that they were being punished [...] It wasn't just college that had just shut down, their whole world had shut down and they were in their house and they didn't understand why. (EPI) ”

Results from the survey (See Figure 2) indicated that the four most common reasons for using technology with people with learning disabilities during the pandemic were to:

- contribute to good mental health and/or well-being
- to help combat loneliness and a sense of isolation
- to help overcome boredom through lack of activity.
- to provide information about the coronavirus and staying safe.

For those who chose the 'other' option the most common reasons given were facilitating the maintenance of contact with individuals or groups that the person with a learning disability could no longer see face to face; and maintaining the provision of a service (e.g. providing day services, undertaking health related assessments, providing educational sessions or attending formal meetings relating to court hearings, care plans etc).

Figure 2: The main reasons for using technology with people with learning disabilities during lockdown



Multi answer: Percentage of respondents who selected each answer option (e.g. 100% would represent that all this question's respondents chose that option)

Examples that interviewees gave of using technology to contribute to good mental health and well-being reflect how they were trying to respond to the stress and anxiety that people with learning disabilities were feeling and supporting them to process their feelings and responses to the pandemic.

“ Yeah, because I do a Zoom group with another group every other week [...] So we just talk and say how we're coping and it's really helpful because we're all quite close as well. You can just let stuff off your chest and everyone helps each other out as well with suggestions. **(SA11)** ”

“ And I think because now, more now than before, there has been a lot of concern about people's mental health. In the lead up to lockdown, people were starting to get quite stressed or were showing signs of having a real problem with it all. I think in a way the leadership team, plus all the staff that were working with people were getting together and saying look we need to do something about this, we can't just do nothing. We have to do something. It doesn't matter how big it is- it can be just a small thing. We need to put something up there [on website]. And so our CEO, he then said, right I'm listening, yes that's brilliant- totally agree with that, let's do it, let's start the ball rolling, let's see what we can do, let's see what's possible to set up. **(SUPP4)** ”

Many interviewees talked about the need to use technology to help people with learning disabilities stay connected with their family and friends, and thus counter feelings of loneliness and isolation:

“ My main concern was that it was all well and good us going in and providing some sort of support by telephone- but actually we are all about connection and it is very easy to fall back into not having connections. For some people who have not been particularly well connected before they joined us. I was quite concerned that people would be starting to feel lonely. We already felt like we were de-skilling people. For example, we had spent a lot of time supporting people to go out and shop for themselves and then all of a sudden we were going: no you can't go out and shop, we are going to do it for you. So it was kind of important to me. It is one of my passions- connections. That is what we are about. So, we asked people who had joined the Facebook group. Once we had established quite a good rapport, we said what do you want to do? **(SUPP2)** ”

Many interviewees also explained that that they were using technology to try and help overcome boredom caused by a lack of activity and loss of routine. They were trying to give the person with a learning disability something positive to focus on each day, in the hope that it would help stop them feeling low:

“ I think a lot of them are very bored because they don't have their usual routines. [...] I have been asked for activities by a lot of people. Having something to focus on has been good. **(SA2)** ”

“ Giving people things to do and things to focus on, positive things for each day. So perhaps each day doesn't feel the same, they do something. Because people's routines have gone, all the things that they look forward to, have gone. Talking about favourite foods if they've got those things in, and going for, doing something nice for themselves really. And we always talk about being kind to yourself, and not judging yourself and getting upset with yourself about how you're feeling, and kind of a bit of stuff about self-care. And helping people to realise that other people are feeling that way as well, and it's natural and it's OK to feel that way. Yeah, I mean people's mental health has taken a knock, and it goes up and down in waves. **(SA8)** ”

Many interviewees talked about the need to use technology to help people with learning disabilities stay connected with their family and friends, and thus counter feelings of loneliness and isolation:

“ Straight away, one of us set up a Coronavirus Facebook page for all the members. In the activity packs that we sent out, I told them all about it, how they could access it if they had the Internet. That has been like a really good source for a lot of people. [...] On there we share things like questions for each day. A lot of the self-advocates have been using that quite a lot to get in touch with each other, and to kind of support each other and everything, which has been useful. Sometimes we put things up like government recommendations and stuff but mainly it is a place where people can have [...] a bit of normality I suppose. Things to think about, like what to do during lockdown. Activities, and stuff like that. So we try and keep it quite light and upbeat. **(SA2)** ”

“ The video that I did [...] was my experience about when I went to the hairdressers for the first time in four months.[...] Because when I first went into the hairdressers there was a big plastic screen and when I walked through the door, she had to put like this temperature thing up at my head to check my temperature. That was a bit strange because I don't usually get that done [...] It's also telling people not to be scared about going to see the hairdresser [...] the video is also telling people that they can just go in just relax and just not be scared and they'll be able to get their confidence up by talking to the hairdresser about what kind of hairstyle they want and stuff. **(SA10)** ”

For many of the supporters, particularly those from advocacy and self-advocacy organisations, their initial use of technology took them outside what they would normally do. But as the pandemic continued, and their confidence and experience in using technologies grew, they began to realise that they could use technologies to enable them to conduct the normal day-to-day activities that they were doing before lock-down. For example, holding staff team meetings, returning to regular self-advocacy meetings, and lobbying or campaign work via Zoom rather than face-to-face.

“ So (refers to person with a learning disability) is very involved in a lot of projects, which have carried on working since lockdown [...] the stop people with a learning disability dying too young group [...] that is based on the LeDeR programme, the learning disability mortality review programme [...] the group continue to meet up on Zoom. They've got lots of actions going forward, so we've just finished writing a big statement which we've sent to NHS England about how people with a learning disability and autism have been adversely affected during Coronavirus [...] So the group have a very strong voice and they've kept working during Coronavirus, so that's been really important. **(SA13)** ”

FINDING 4: THE PRACTICES THAT REMOTE SUPPORTERS ENGAGE IN WHEN USING TECHNOLOGIES TO SUPPORT PEOPLE WITH LEARNING DISABILITIES CAN BE CHARACTERISED AS SPEEDY, EVOLVING, CREATIVE AND FEARLESS.

With the exception of two parents who were living with their adult-child with a learning disability all of the supporters that were interviewed were providing support remotely. This remoteness placed particular challenges on them, but the practice(s) that they developed can be characterised as:

- Speedy
- Evolving
- Creative
- Fearless

The majority of support organisations, day services, self-advocacy groups, advocacy groups and charities reported that they were using technologies within days or weeks of the start of lock-down.

“ I think probably the week before lock-down we started talking about how we would use Zoom and what that could be like. Not thinking actually that it would be really that successful. We have probably about 130 service users across the centres. We were just trying to think about how we were going to capture everybody and make sure we didn't miss people. Checking in with people really. We were still very much thinking about the physical side of it and phone-calls and things like that. But we had the idea that we could certainly do things like dancing on Zoom. Then, on the Monday, we realised that we were going to have to close. The next day we were all obviously really gloomy and sad and then we said: right we need to do it. So, we put up a Zoom timetable for the following week and then we spent time going through every service user, contacting them and their circle of care and saying, can you access it? Sorting people out with passwords and really just talking them through on the phone: right click this button, now press that now, now do that now. And getting to grips with the meeting codes. **(PROV1)** ”

Conversely, local authority run organisations appeared to be quite slow with regards to how long it took them to decide to use technology with people with learning disabilities or to implement that decision once made:

“ Obviously, the pandemic developed very quickly- our services shut I think on the 20th or 23rd of March very suddenly. [...] They all spent time at home with their parents, living alone or in residential or supported living. At which stage it took [the] organisation a couple of months to work out how best to support those customers- apart from immediate urgent need. Which is when we then started to develop our technological response. **(PROV2)** ”

“ We had to produce stuff and send it through to a lady who was very good at IT- to put it on the website. But it was probably about three weeks before anything started going on the website. **(EP3)** ”

The practice of many supporters evolved over time. For many this evolution was part of a learning process, where, through trial and error they tried out different technologies or different ways of using technology, learnt which worked best and adapted accordingly. One employee of a support organisation described how practice evolved in their organisation from giving people instructions on how to use WhatsApp on their mobile phones, to ensuring that people had iPads and Internet access to enable them to use WhatsApp. As people became aware of Zoom, practice evolved to include running Zoom-based meetings and activities. They also set up a closed Facebook group for people to chat and share experiences. In another example, a college lecturer described how her instinct was to use video to teach cookery remotely, but her use of video changed over time, with experience:

“ Initially I was making demos, my daughter was videoing me and then I was posting them up and getting them to watch them, and then talking them through. But I ditched that really quickly and I actually did the cooking live [via Zoom], which was a lot of fun. And then gradually I got the learners doing it at the same time as me, but that depended on setting up the laptops in their kitchens and really, it was really complicated. I'm very lucky, I've got a garden room, so I decided to ditch anything that was going to be cooked on a hob [...] We made a noodle salad, we made pesto, we made something every week. **(EP2)** ”

For many this evolution of practice reflected a curiosity about what might be effective ways of engaging people with learning disabilities remotely or a culture of learning:

“ We were learning on our feet. So things that we did within the first two weeks of the pandemic-with technology, we do totally different now. Because we have learnt by developing, by our learning, we have learnt different ways. **(PROV2)** ”

“ Also, I think the attitude from some managers and staff have just been having a go, some staff were quite curious to see how the service user would engage. **(HCP1)** ”

Some support practices were creative in that they were informed by prior or unrelated learning experiences and adapted for use with people with learning disabilities:

“ Because I am a deacon in our local church, and I am also a lay preacher I had already experienced this, and we were already doing church on Zoom. So, I had actually crossed the IT barrier in the other part of my life. So, I was able to draw on a lot of those skills and then feed them into what I was doing. **(EP3)** ”

Some support practices were creative because they sought to move away from mandated standardised practices and technologies:

“ Oh. So basically, if they didn't have their own smartphone, in the beginning, we were looking at options for them [...] The directors relaxed the phone policies so staff could help with their phones to keep people in contact with their families and things like that on WhatsApp and video calls. **(SUPP3)** ”

Some support practices were creative because they involved a large amount of persistent problem-solving, particularly when trying to remotely set up and install new technologies or work out why something did not work.

“ Again, one person had lots of difficulties with it. The other two did quite well. So, we ended up, I would connect to Jitsi and this person would call me via WhatsApp, and I would hold my phone towards the camera and the computer. He would be participating, and the other people would see him that way. **(OTHER)** ”

“ There is one lady who usually lives in a residential home- she went home to be with her mum during the lockdown- who has got the starting of dementia. So of course, she was cut off from her day service friends, she was cut off from her residential home friends and her mum couldn't quite cope with the technology-although they had two tablets and a laptop. So, we had one of our staff members on the phone to her for four hours trying to sort it out and then another one the next week. But in the end, we have managed to get them onto Zoom. So now both of them are less isolated and that is fantastic because the lady can see her friends at the residential home. She has joined the gardening quiz sessions- her mum has been able to attend the Zoom partnership board meetings as well. So, it has had a positive impact on all of the family in that way. **(PROV2)** ”

Some support practices were creative because they found ways to provide technologies for those people with learning disability that did not own or have access to technology:

“ We actually went out and we got some funding to actually go and buy some tablets as well for members. And a member of staff actually guided them through the help to set it all up there and use it. Which is good, so they can take part in all the activities. Because we thought it would be good for them to learn new technology, and we will continue using this once the pandemic is finished. We thought it was a good investment. **(SA7)** ”

Other support practices were creative because they sought to put in place strategies for addressing issues of risk, particularly in relation to Internet safety.

“ Once I got clearance from my manager that they would let me use Zoom- because originally, we were told that we must still use Google Meet. Very few of my parents could get their head around Google Meet or wanted to use it. So, when I said, I can set Zoom up with a waiting room, I can cover all the safeguarding elements, I know how to do that, they said “well yes alright”. And that worked really, really well. **(EP3)** ”

When describing their practice, it became clear that many supporters were not afraid to step outside of their comfort zone and try new technologies or ways of using technology.

“ In my life things go wrong and I think it's just accepting that you know, as long as you're able to justify that it was for a good reason that's - it's one of those things isn't it. **(SUPP2)** ”

“ With other parents, it was “Oh let's give that a go”. And sometimes it went wrong. The good thing about it, is if it's gone wrong, we have taken a fairly pragmatic approach, we've said, “Oh that has happened, can we work out why it has gone wrong? Let's see what we can do”. But we have not stressed or worried about it. **(EPI)** ”

Furthermore, when asked what advice they would give to other supporters who were thinking about using technology with people with learning disabilities, but had not yet done so, the majority of interviewees responded that it was important not to be afraid of failure.

“ Just do it. Like the Nike thing. Just do it. Don't worry. Don't panic. Don't try to overthink it. Don't try to over-plan it. Just do it. Just have a go. If it goes wrong don't worry, you ain't going to kill anyone by messing up a Zoom call. **(EPI)** ”

“ I would say, “Do not be afraid”. I'd say, “Kind of try and do a bit of trial yourself in advance”. [...] I think what I would say that even if you're not confident. they'd get a lot out of it, and even if speech and communication is a difficult issue, I'd still be prepared to try it because there's lots of things you can do. **(PAR2)** ”

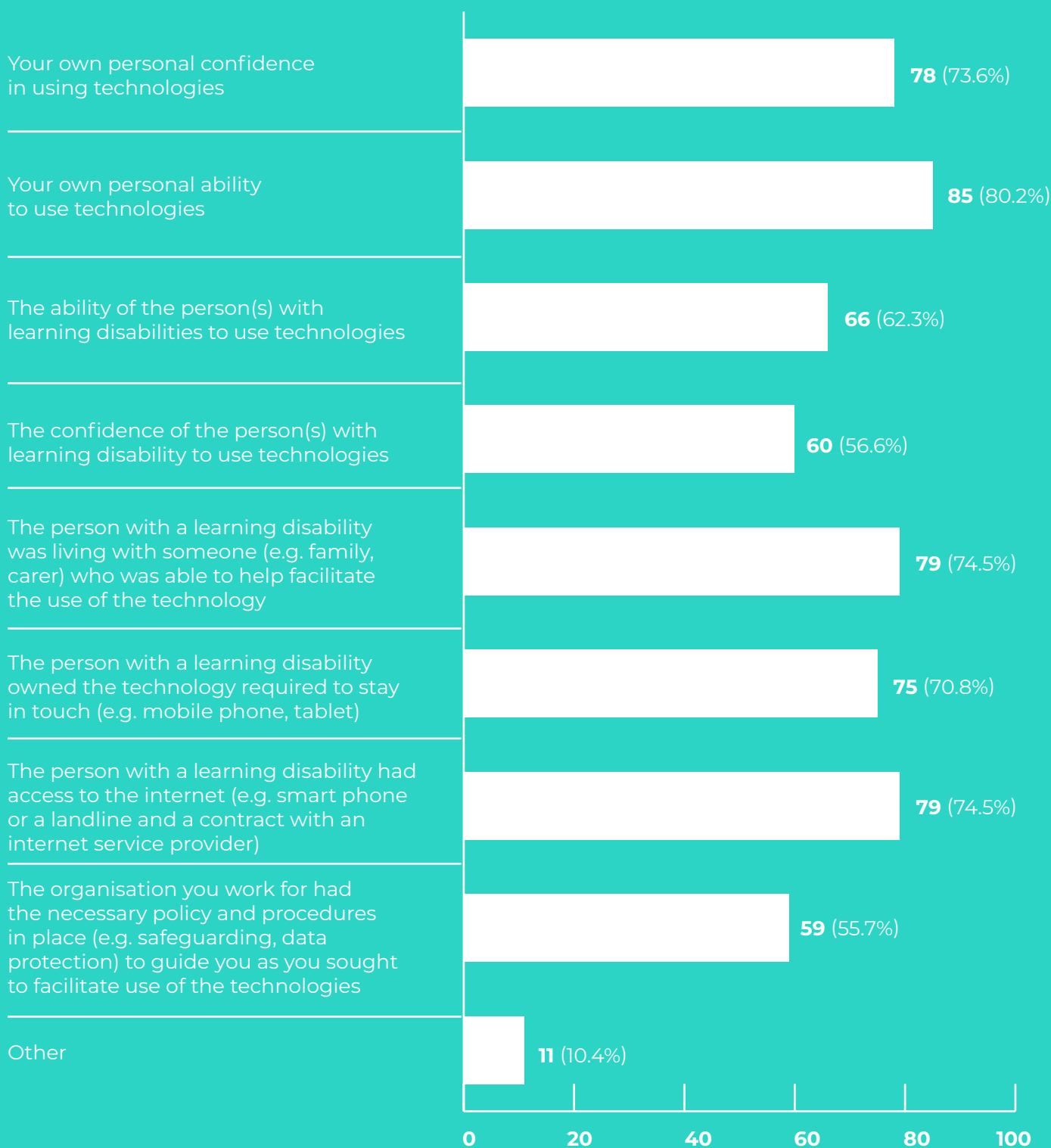
These speedy, evolving, creative and fearless practices were often made possible through the training and support provided by the supporter's employer or organisation:

“ As the lockdown went on [...] we had access to funding which meant that every house [...] had access to a tablet there, and we were then able to talk through the staff how to download Zoom and we had training. **(SUPP3)** ”

“ I spoke to my manager and they were happy for me to try using stuff. The college does stuff through Teams. I don't like Teams because you can only see a limited amount of people. I think in these concerts I had seen the Rolling Stones and Elton John doing their stuff using Zoom, so I thought let's have a go, let's see if we can do that. So, I spoke to the parents, because none of the students are able to log on independently, the ones that I teach in my main group. Essentially the parents are being the support workers. And there were quite a few desperate parents at that time. It was a case of well anything is better than nothing, let's just give it a go. That was absolutely fine. So, I thought right, we'll do this. So, I installed Zoom and sent it out using my works email address. **(EPI)** ”

FINDING 5: ONE OF THE MOST SIGNIFICANT FACTORS THAT ENABLES PEOPLE WITH LEARNING DISABILITIES TO USE AND BENEFIT FROM TECHNOLOGIES DURING LOCKDOWN IS SUPPORT FROM SOMEONE LIVING WITH THEM

Figure 3: The factors that have helped to support people with learning disabilities to use technology during lockdown



Multi answer: Percentage of respondents who selected each answer option (e.g. 100% would represent that all this question's respondents chose that option)

In another example, a college lecturer described how a parent of one his students supported them to make videos and then share them in a Zoom session.

“ We have got another student [...] his dad was quite reluctant for him to access technology because he was worried that he would use it inappropriately and get himself into trouble. This was before the Zoom sessions. Now they make videos almost every day and the student loves them. He is starting to catalogue them and put them all together and really enjoys that. They put them (videos) on a laptop or a device and then dad holds up his phone to the screen. So I then spotlight it, make it nice and big for everyone so they can see that. **(EPI)** ”

A support worker in a supported living home shared how the organisation she worked for provided a laptop, a mobile phone and access to an online chat facility called Yammer to every home. Staff in the home were permitted to enable the residents with learning disabilities to use these technologies if they needed to:

“ It probably started back in the day before smartphones were the thing. And so every team had a netbook or a laptop and a team phone. Even the team phones at the moment are the old Nokias, not the smartphone. But we are about to get smartphones in all the teams. The reason it started was because some people don't have their own smartphones or laptops at home to access their emails and things like that. So it was about keeping people connected. And if there were team meetings, they could be minuted [...] Basically, it is for the people that we work for to use [...] Most people would prefer to have their own if they can afford it, but if they can't, then it's there to use as long as they use it appropriately. At (name of the organisation) people are encouraged (to use technology) because it is a skill, and it shouldn't just be for people who are employed to have. It should be for everyone to have that skill if its available. **(SUPPI)**. ”



FINDING 6: THE MOST SIGNIFICANT BARRIERS TO ENABLING PEOPLE WITH LEARNING DISABILITIES TO USE AND BENEFIT FROM TECHNOLOGIES DURING LOCKDOWN ARE THE DIGITAL DIVIDE AND LACK OF IN-HOME SUPPORT

Results from the survey indicated that supporters experienced a range of difficulties when trying to use technologies with people with learning disabilities. The most frequently reported difficulties were: the person with a learning disability not knowing how to use technology or not owning technology; there being no-one living with the person with a learning disability who could help facilitate the use of the technology and poor Internet connectivity (See Figure 4). Additional comments that survey respondents made regarding the difficulties they face suggest that digital exclusion and lack of support, particularly in-home support, presented the most significant barrier to enabling people with learning disabilities to use and benefit from technologies during lockdown:

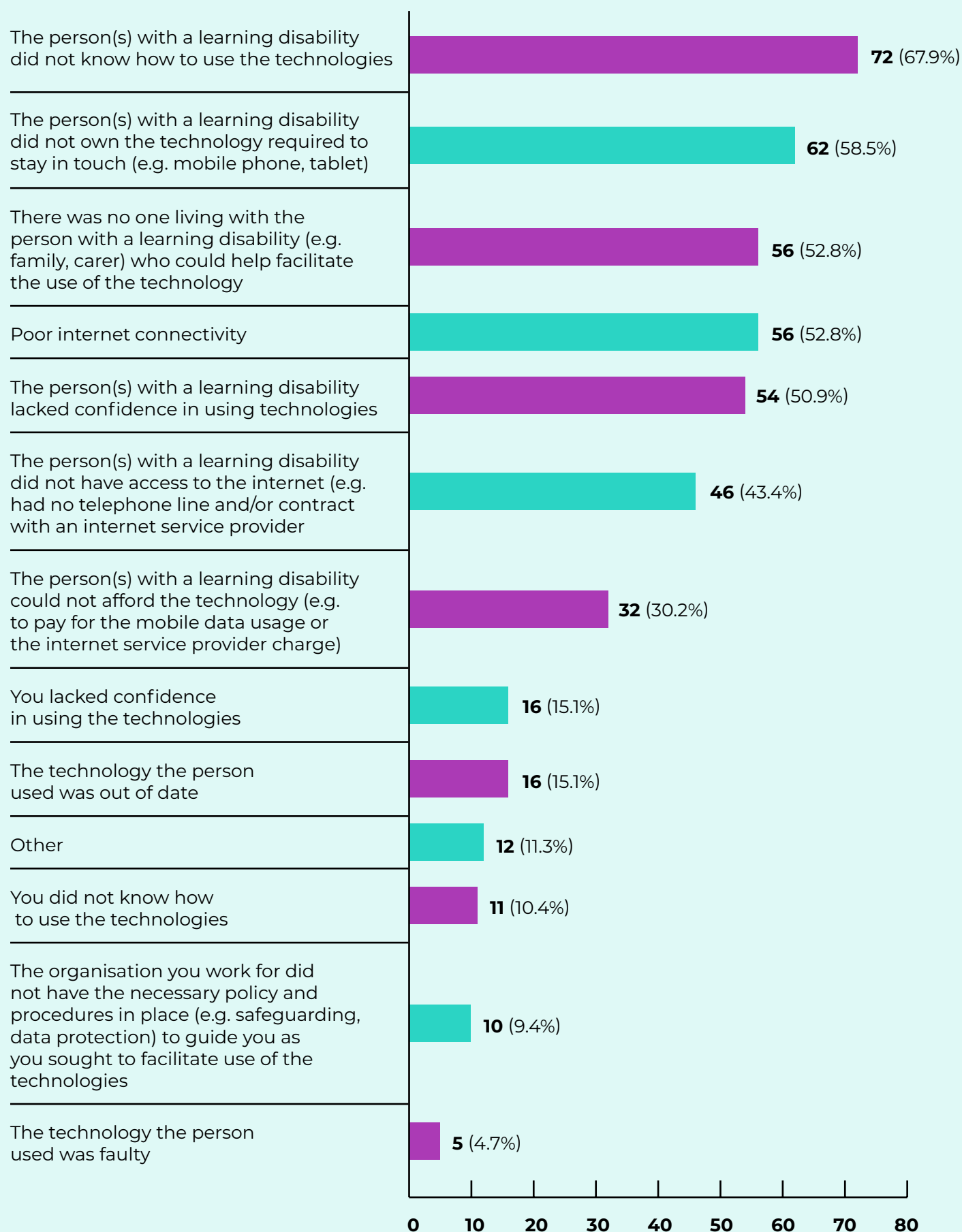
“ I’ll never get over the presumption everyone just has kit, data and skill, a senior manager actually said, “ you can just use your mobile phone”. No clue about access needs at all. Digital inclusion should be one of the first questions on any assessment.

[..] we have members that, apart from phone calls, we have not seen at all because there is no-one with them to support access, even though they want to continue seeing their friends and taking part in a shared activity. It makes me so sad that there are care services who cannot do the same due to lack of resources, confidence or whatever.

”

Experiences shared by the interviewees also revealed a range of technical difficulties that they had to try and overcome which meant that if the technology did not work, the person with a learning disability who they were supporting would get frustrated and give up. It could be hard to persuade them to try again when the technology did finally work. Other practical problems encountered included: problems remembering passwords and finding someone in the support team who knew them and problems finding somewhere private to engage in online chats if the person lived in shared housing and the technology was located in a communal space. However, like the survey data, the interviews indicate that the most significant barriers were The Digital Divide and Lack of In-Home Support. We will discuss each of these in more detail.

Figure 4: Barriers to supporting people with learning disabilities to use technology during lockdown



Multi answer: Percentage of respondents who selected each answer option (e.g. 100% would represent that all this question's respondents chose that option)

THE DIGITAL DIVIDE

For some people with learning disabilities the reasons for being digitally excluded are similar to those that have been reported in relation to those who are digitally excluded who do not have a learning disability. For example, there were occasions where supporters identified that it was more common for younger people with learning disabilities to be using technology during lockdown than older people:

“ We have got quite a young group of people. Whether that makes a difference. I think it does a bit- they have smart phones and are very aspirational in terms of what they want to be able to access. Lots of people have smartphones, iPads. I don't know about computers at home. **(SP1)** ”

There were occasions where supporters identified that people with learning disabilities were not able to access Wi-fi or afford data in order to access the Internet:

“ Before lock-down we didn't know which of our self-advocates had the Internet at home. I think some of them would have smart phones on them. But it has been interesting through this (pandemic) because I think I assumed that quite a lot of them had Wi-Fi at home, but actually what they have had is data, which does make a massive difference. Because (data runs out easily), it means that they can't do things like Zoom and things like that. **(SA2)** ”

“ The majority of our families, of our parents, will have smartphones. [...] there are kind of issues around that [...] just affording data. [...] they tend to be on the [...] higher end contracts, because maybe they haven't understood, or they've been 'up-sold' in terms of the phone they have. **(SCP1)** ”

There were also occasions when, in addition to other factors, Internet connectivity was a frequent barrier to accessing the Internet:

“ The technology is what it is, it's Devon. So sometimes we lose people all together. We can lose days really, effectively, if there are seagulls on the line or something happens! For me, the other issue is cost for people as well. A lot of them have smart phones but they don't necessarily have a good Internet package. There are lots of things like that, where people can't afford it. For the chap who had the mental health problems all of the referrals that we made came back to an online application [...]. He couldn't afford the Internet, so he immediately gets bounced out of services before he even gets a foot in the door. **(AD4)** ”

Several of our interviewees reported their dismay at how disinterested local authorities and others were in supporting people with learning disabilities to access technology before and during the lockdown:

“ There were people who just straight on it and didn't need any help. They were ready. There were people that needed the phone, just for reassurance and not to panic. We got lots of panicky messages on Facebook: I am trying to get into choir, and I can't in- that sort of thing. And then the flat refusers really. Who just- maybe they don't have internet at home, or its just totally beyond them? We have got a couple of people who sadly really want to do it- but their parents won't enable them to use the Internet, because they are worried about the Internet- safety and all that kind of stuff. So, it's been a mixture, but like I said, probably 80% positive. **(PROVI)** ”

For many of the interviewees lock-down has raised their awareness regarding how digitally excluded people with learning disabilities are and the need to enable them to access technology and get online:

“ Technology plays a huge role in everybody's lives and what I feel is that people with disabilities often don't have access to those technologies. They are the ones that need it the most. Lock-down has showed us how important it is that people with all disabilities have access to technology, that they have opportunity to play and learn how to use them- so that when lockdowns happen they can stay [connected] because they are the most vulnerable when lock-downs happen. We are likely to have those situations again in the future, so for me I want everybody to have access to an iPad or a smartphone or a device that will help them to stay connected. Giving them opportunity to be in contact with their friends. **(OTHER)** ”

“ [...] our director's making a bid for funding to look into digital access for people with learning disabilities as a result of doing this whole lockdown thing, because it's something that we see as a big problem. So even if we're coming out of COVID moving forwards, we're going to be looking at this issue and trying to work out how we can get more people online [...] Everything's going online now. If you go to the job centre, they want you to do everything online, the GP wants you to do everything online. Now all the government departments want you to do everything online, and it's really excluding for people. This situation has just highlighted and really brought that to light. So, it's something that we're going to work on for the next coming years hopefully. **(SA5)** ”

Whilst it is important to recognise how digitally excluded people with learning disabilities are compared to other groups in society, data from our interviews also indicate that there is more than one kind of divide. In addition to the divide between people who have learning disabilities and the general population; amongst people with learning disabilities there are huge variations in technology access, use, skill, and confidence:

“ There were people who just straight on it and didn't need any help. They were ready. There were people that needed the phone, just for reassurance and not to panic. We got lots of panicky messages on Facebook: I am trying to get into choir, and I can't in- that sort of thing. And then the flat refusers really. Who just- maybe they don't have internet at home, or its just totally beyond them? We have got a couple of people who sadly really want to do it- but their parents won't enable them to use the Internet, because they are worried about the Internet- safety and all that kind of stuff. So, it's been a mixture, but like I said, probably 80% positive. **(PROV 1)** ”

Whilst some people with learning disabilities do not have access to technology, others do:

“ One of the things, one of the massive barriers that we know affects people with a learning disability [...] is the lack of, not everyone has access to a smartphone or a computer or wi-fi. **(SA13)** ”

“ We know that people who work, people that are in jobs often have the technology. So will have [...] smartphones or Android phones or a tablet. What's been interesting is and lovely to see is that some people didn't have any technology. So some of our colleagues who maybe had a spare laptop or a spare tablet have actually right at the start of social distancing just dropped the laptop outside somebody's house or dropped a computer outside. So the person might have had the internet but not a tablet or a laptop to use. So that's been really nice to see. **(SA12)** ”

Whilst some people with learning disabilities have no interest in using technology, others do:

“ We've got an awful lot of members that won't access anything online at all. **(SA7)** ”

“ I think she has just worked away at things on her own, because that's what she's wanted to be able to do. Which is great, it's great, it has given her an advantage I think in the pandemic that some people will not have had. **(PAR3)** ”

Whilst some people with learning disabilities do not have the skill or confidence to use technology, others do:

“ Most have a mobile phone. Lots of them can't use the mobile phones very effectively and don't even answer if it rings because they don't know how to. **(AD3)** ”

“ She has done Skype before, my dad used to Skype in the past, to Australia with her. He used to have her one day a weekend for the day and I think they used to use Skype, so she has done that in the past. She has done some IT stuff as well, I mean London, one of her day placements - she did an IT course one morning all week, so she has used some technology - she's not using anything here but that's another thing isn't it? I mean for her, day activities here, there's no technology really being used. But there's - you know, as I say she did an IT course, she's got a certificate somewhere that she's got for digital photography. **(SIB1)** ”

Whilst some people with learning disabilities have had good support to enable them to access and use technologies, others do not, particularly those living independently:

“ [...] the organisation had setup, for those that wanted them, a sodal card which is a pre-paid debit card, so that that way he could order things online. So he has been enjoying the freedom of being able to order things online rather than going to the shops to buy them. He has been looking up things that he needed for the house quite a few times, or his shopping, trying to get a delivery slot. **(SUPPI)** ”

“ We have not been able to videoconference with people who are living on their own, because they have not had any kind of support to enable them to use the technology. **(PROV3)** ”

Overall, the evidence we have found regarding multiple digital divides, suggest that the traditional solutions for the digital divide of providing people access to technology and teaching them how to use it will not be sufficient when engaging with people with learning disabilities. Additional factors are at play and one of the most influential of these is support, particularly in-home support, as we will outline in the next section.

LACK OF IN-HOME SUPPORT

For people with learning disabilities living in residential care homes or supported living, their access to technology is mediated by the staff who work in those homes. As one self-advocate said:

“ They’re gatekeepers, but they’re always gatekeepers, they’re gatekeepers even outside of lockdown. **(SA10)** ”

Results from both the survey and the interviews indicated that a significant barrier to being able to support people with learning disabilities to use technologies during lockdown was the quality of support provided by these gatekeepers. When parents, siblings, advocates, self-advocates, support organisations and day services tried to use technology to contact a person with a learning disability who was living in a care home or supported living the chances of them being successful was dependent on the availability of someone to support the person with a learning disability to answer the call and stay connected. Some of the self-advocacy groups felt that they were having to ‘fill in the gaps’ that ‘should’ be the role of support workers (See ‘Filling the Gaps’ report for more detail).

Some respondents gave examples of non-existent support:

“ Then we had another student who was in a care home and we were told that he couldn’t join because he didn’t have a laptop. So, I entered a competition and I won him a laptop! So, he had got a laptop, they had got wi-fi in the care home, but he still couldn’t join because he needed the care workers to do that. I don’t know. It shows you, that with students with severe learning difficulties they are totally dependent on care workers. **(EP1)** ”

Some respondents gave examples of support being “a lottery”, being highly variable, depending on which staff were on shift. For example, one sibling shared how her sister was supported by a range of staff in a supported living home. Two of these support workers appeared to be confident technology users themselves and understood that her sister wanted desperately to use technology to keep in touch with her family. The sibling describes how she and her husband bought a Facebook portal, connected it up to a smartphone, wrote some instructions on how to use it and then took it round to the house. They were able to engage the support of these two support workers to set it up in the house and enable the sibling with a learning disability to use it:

“ [...] so what we had to do was we had to completely disinfect everything, we had to hand in you know, through a door to the carers, with a set of kind of instructions, because we did this sort of help sheet for the carers. [...] So that was absolutely brilliant, we have gone up and been standing outside the window, so they could see us there, and we could sort of see the screen, and we could say, could you touch that,? could you move that? I think there's a kind of mini server, a booster box, so they were going to have to do all that. They were amazing. They were really good. We were standing outside the window and could say to the girls (support workers), that's what that means, if you put that in there that will work. **(SIB2)** ”

However, when those two support workers were not on shift, the support available to the sibling was highly variable, with many lacking the skills and confidence to help her if the technology was not working:

“ [...] the downsides were if something did happen and we couldn't fix it, we had to wait for a carer who knew what to do, and obviously with rota's and things like that sometimes it didn't happen [...] she saw as well some carers just couldn't do it, they didn't have a clue. [If] something went technically wrong, I [would] hear her saying “Quite honestly, I don't know, but (name of support worker) is coming tomorrow”. **(SIB2)** ”

In another example, this time a care home, one respondent shared an example where a care-home was unable to provide consistent support or support that would enable sustained or meaningful use of the technology:

“ I had one learner, this was so hard, she's got a hearing impairment, she's in a home and the first week she joined they put the screen up in the main lounge. And it was obviously very loud, and she could hear me, and she was just beside herself. She was so happy to see me and the other learners, she was so excited. And I could see other people in the room watching as well, and it was great. So, we were so thrilled to have her. And then the second week she was in her room with her laptop and she couldn't hear. And the assistant, he was all masked up and he came in and he made sure she was online, and then he left her, and then she couldn't hear. So, we spent the whole session, we had visual signs, we were trying to engage her. She was happy to see us, but she couldn't engage at all. And we kept trying to encourage him to stay. We kept saying would you be able to stay? And he was like I really can't because I've got the other residents. So, she spent most of the sessions not engaging [...] **(EP2)** ”

Some respondents shared examples where the staff seemed to be resisting providing support to access technology, seeming to find a range of excuses for why it was not possible:

“ [...] they live in a group home run by a private organisation. And the manager there, I emailed her. [...] some easy read guide to using Zoom, so I sent her that. An organisation [...] have made a video explaining how to get on Zoom. So, I sent her the link to that. And our website now has pages on it, including all the things you can do online. Never even got a reply. So, the weeks went by and I kept on communicating with them through Facebook messenger and I kept saying “ring me and we’ll sort out a time to try and help you with this”. **(SA1)** ”

“ And I phoned up one care home company a couple of months ago now [...] And that was an eye opener because we’d had so much success with some supporters and I phoned up and spoke to some young guy who said well I can’t really get them online because our computer’s really old, it’s got no webcam and they wouldn’t understand anyway, because they’re from a different time. And I was like oh come on [...] but I just said well really, surely it would make your job far more satisfying if you could do it and you could support somebody to do it, it’ll be good for all. But we didn’t get anywhere. **(SA6)** ”

Many respondents recognised that staff working in care homes and supported living were doing a difficult job during lockdown and that many of them were overstretched. But overwhelmingly, respondents highlighted underlying systemic or cultural factors why carers and support workers might not always be inclined to help people with learning disabilities, in or out of lockdown.

Sometimes lack of in-home support was attributed to a lack of technical skill and confidence:

“ Some residential homes-staff aren’t that familiar, or they have only got kit that staff can use, or they are anxious about using Zoom. **(PROV2)** ”

“ So there’s quite a lot of older women working in the care sector, so when you talk to someone at someone’s house, they go well I don’t know, I don’t really know what to do, I don’t know what you’re talking about. **(SA5)** ”

Sometimes lack of in-home support was attributed to restrictive views regarding who was permitted to use technology owned by the care home or supported living organisation:

“ Some of the homes said that they did not have equipment. Some of the smaller homes where there's maybe only two or three residents, I was told that often the manager of the home had the laptop for their admin and that was all they had. So, the residents didn't have any access and didn't have any equipment. So that seemed to be one thing that was holding them back. **(EP2)** ”

“ [...] the barrier is if the staff aren't there to help them set it up and get permission. So, all the communal computers, they have to get permission and they have to get help to set it up. And sometimes that is quite difficult, because the staff aren't always about. So that's really difficult for lots of people because staff could be busy or not got time or whatever and so they lose out because of not connecting to a computer, which is really sad. It is really sad. **(SA8)** ”

Sometimes lack of in-home support was attributed to outdated conceptions of what 'caring' means:

“ They haven't got that motivation to push themselves out their comfort zone. They're there to be comfortable. They're caring people, they want to care for, they're not there to empower, [...] They have that caring but they don't have that forward-thinking element. **(PROV3).** ”

FINDING 7 USING TECHNOLOGY TO SUPPORT PEOPLE WITH LEARNING DISABILITIES DURING LOCKDOWN HAS HAD A POSITIVE IMPACT ON THEIR MENTAL HEALTH, WELL-BEING, SENSE OF BELONGING AND CONNECTEDNESS

Negative impact of the lockdown

The participants in the survey and interviewees reported that the lockdown had three main negative impacts on many of the people with learning disabilities that they supported. People with learning disabilities experienced a great sense of loss and boredom because their routines were disrupted, and they were no longer able to engage in the activities that they valued and enjoyed:

“ Well me personally, even though I’ve got autism as well as a mild learning disability, I feel as if my routine’s gone out of the window. Because I’ve got used to going to work Monday to Wednesday and then have Thursday and Friday off [...] So, I just feel like my routine has gone, it’s disappeared. **(SA12)** ”

People with learning disabilities experienced a persistent sense of anxiety because it was not clear when they would be able to return to these regular routines (e.g. speaking with family, engaging in self-advocacy group meetings or attending day services or college):

“ So like, in the build-up for me stopping going, I began to talk to her in those last few weeks about things, but for her it was like a bereavement, I was there all the time and suddenly I was not, so in the first few weeks I got quite a few distressed phone calls, where she’d be like “are you ever going to come and see me again?” **(SIB1)** ”

People with learning disabilities experienced significant loneliness because they were missing out on social contact with family, the friends they had made whilst attending regular pre lockdown activities, as well as paid for support that was suddenly withdrawn. The isolation of lockdown was not only resulting in loneliness, but also a loss of confidence:

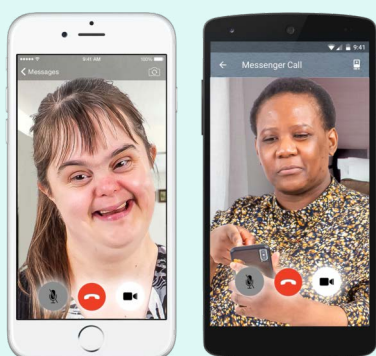
“ I just feel isolated, I feel alone. I suppose even if you’ve got loads of people around you, you can still feel lonely and I have my carers come in three times a week for nearly all day, but I still feel alone. I feel like I’m not connected to the outside anymore. I feel like [...] my confidence has got lost to go to the shop. **(SA8)** ”

FINDING 8: USING TECHNOLOGIES TO SUPPORT PEOPLE WITH LEARNING DISABILITIES DURING LOCKDOWN HAS HIGHLIGHTED THE TECHNOLOGICAL CAPABILITIES OF PEOPLE WITH LEARNING DISABILITIES AND THE POTENTIAL OF NEW SUPPORT PRACTICES

Many participants spoke of how the successful use of technology by people with learning disabilities had revealed to others how capable they were and what it was possible for them to achieve. The achievements mentioned are varied and include being able to explain to a support worker how to use Zoom; having the confidence to create a quiz and host it on Zoom, holding trustee meetings online, filming lockdown experiences and putting them online and creating or participating in YouTube videos:

“ One of the people we support actually made the local papers about staying connected during lockdown and he had a birthday party in lockdown and I was able to get his staff team on my phone and his family on his iPad [...] one of his things was “If this global pandemic hadn’t happened and there wasn’t a lockdown, I’d have never have learnt to use video calls would I?” **(SUPP2)** ”

“ Also, people have contributed. We have got a couple of service users who have said: I would like to write the quiz. Separately- via email or Facebook- I would like to do this. And so, people are really being able to have much more input and lead what they are doing [...] It’s been great to see those people flourish in that way. **(PROV1)** ”



The ability of people with learning disabilities to learn how to use new technologies during lockdown has been a source of pride for many of them but has also surprised their supporters and opened up their eyes to what is possible.

“ Lockdown shows what we can do, and we can do more than before [...] It shows you what you really can do. Technology’s opened it up to people, so they have to listen. **(SA6)** ”

“ I’ve been amazed at some of the service users who have taken it on as well. People who I would never have thought would have done. And for an example one of our other groups is an older person’s group. And I was looking back at my notes the other day because I was the one that was tasked with doing the online protocol and everything. And my original notes said something like that it wouldn’t be appropriate for that group, because we didn’t think it would. We just didn’t think it was possible. And actually [...] that group, with the help of the people that they’re living with and stuff like that, they are more or less all in that group online and meeting every two weeks as they did before. **(SA11)** ”

There are also occasions where participants have shared how people with learning disabilities who had been resistant to learning new to use technology before the lockdown, have realised, through their use of technology during lockdown, that learning how to use new technology is not as hard as they thought. This has the potential to open their eyes up to what else they might do or achieve.

“ The artist who is now talking about getting a tablet. We were always going on at him. He can work a digital camera; he can work a video and DVD player. It was never going to be that much of a leap for him to be able to work a tablet. But he just had a mind-set where – he was going to make mistakes, it was too complicated, he was going to do something wrong. This crisis has thrown him into a situation (where he has realised) actually I am missing out on something here. **(PROV3)** ”

“ And I think the fact that (she) was so desperate for contact made her try things that maybe she’d have been quite resistant to, because she’s not a proactive person, but if she wants something she’ll get it, and she knows her own opinion, but she’s quite resistant to trying out new things, but if they don’t work she gets disparaged quite easy, but hopefully now she’ll start thinking of other things. **(SIB2)** ”

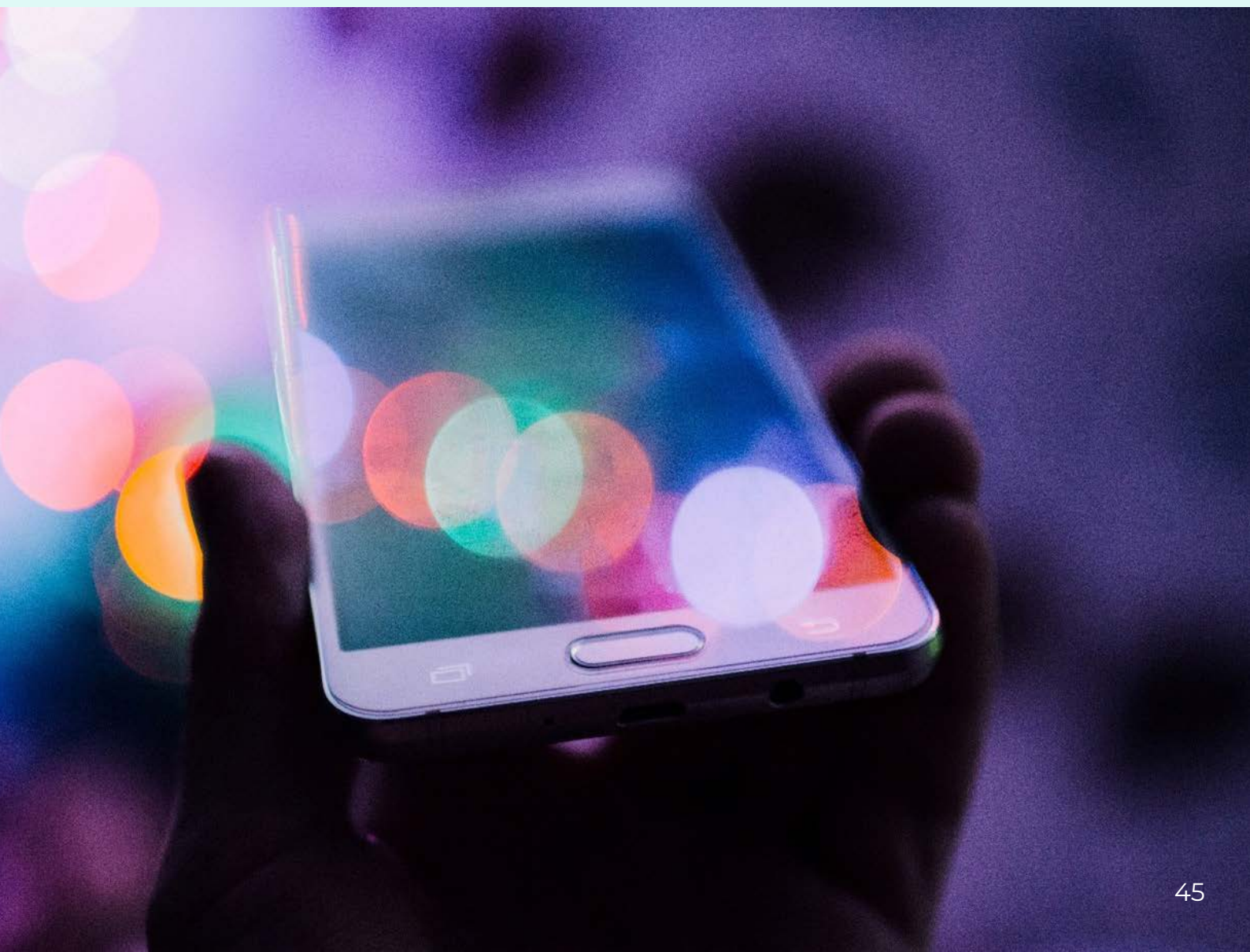
Finally, the use of technologies during lockdown had opened the eyes of some supporters regarding how their new technology enriched practice might carry on or be developed, post lockdown:

“ I think we will definitely continue to have some meetings via Zoom. I think it will be invaluable really. And I think we will be able to consult with them actually, much more often. And maybe even sometimes a bit more spontaneously. **(AD1)** ”

“ I was talking to a couple of members the other day, and they said do you think you'll keep the Zoom going? And I said well I'll keep the Zoom going as long as people want it really. And they said there's something nice about you all from all different parts of Norfolk talking to each other. Getting to know each other, and that's quite nice. **(SA8)** ”

For many, these new practices have been made possible, because of the pandemic. Supporters would not have thought they were possible without the trigger that COVID-19 provided:

“ I think a lot of our colleagues said to us if you'd have said in January, we would have all been working like this, we would have said that's never going to work. And I think COVID-19 has, Coronavirus has pushed us into using technology, so it's pushed some people into using it. But then also the benefits of it have been, lots of people are saying oh this is really good and are we going to carry on when we get back to working normally. So I think that it's a really interesting time, so yeah that's me. **(SA12)** ”



CONCLUSIONS

The results from our study reveal two important issues.

- Technology has an important role to play in helping people with learning disabilities keep connected and stay well during the pandemic, and indeed that there are benefits to technology use beyond the pandemic.
- For those people with learning disabilities that do have access to technology, both remote and in-home support is vital to enable them to use it successfully and persistently.

Our study also revealed that many people with learning disabilities were excluded from benefiting from the use of technology. The main reasons for this are because:

- They do not have access to technology and in many cases this is because of the poor policies, practices and cultures of the organisations that care for or support them
- They do not have access to in-home support to access and use technology. There is potential for the support to exist, but the conditions are not in place to enable that support to be available (e.g. support workers and/or family members who have the skills and confidence to use technology).

The experience of using technology to support people with learning disabilities during the pandemic has led many supporters in our study to conclude that it is necessary to try and address this digital exclusion, to close the gap between those who are able to access and use technologies and those who are not. They talk about the need to plan for both the short-term and the longer term.

To prepare for the next lockdown or pandemic:

“ Because what we’re trying to do now is future proof it, so if we do get a second wave people are prepared. That’s what we’re trying to do. We’re trying to now set up the next stage of one to one meet ups where people can bring their tech, and we can set it up for them. If and when it does all kick off again people are a bit more well connected than they are at the moment. **(SA8)** ”

To continue and develop technology-enriched practices beyond the pandemic:

“ It’s not as bad as you think it might be, and there are some unexpected positives and plusses using technology here. I think if we can support people with learning disabilities to become used to it through exposure and repetition, it does open other doors. **(HCPI)** ”

In much the same way that during the pandemic Zoom has caused many of us to re-imagine how we connect with our work colleagues, friends and family; using technology has caused many of those who support people with learning disabilities to re-imagine their practice.

RECOMMENDATIONS



For many of the people who participated in our study the COVID-19 pandemic has opened their eyes regarding how they can use technology to support people with learning disabilities and the positive outcomes of this technology-enriched support. New possibilities have opened up for them and the people with learning disabilities that they support. In order to avoid these possibilities closing down and the continued digital exclusion of many people with learning disabilities we make the following recommendations:

EDUCATION, HEALTH AND SOCIAL CARE PROVIDERS AND COMMISSIONERS

1. Collect detailed information about what technologies the people with learning disabilities that they support currently do and do not have access to and what they would like to have access to and be able to use. Create a detailed picture of what the digital divide looks like in their context.
2. Plan how to fund, set-up and distribute technologies to those people with learning disabilities who do not have access to technologies. But don't provide access to new technologies without also ensuring that the person with a learning disability and their in-home supporters know how to use it and can afford to use in the case of mobile phones and data.
3. Develop and embed in the practices and cultures of those organisations that deliver education, health, and social care innovative capacity-building programmes for both people with learning disabilities and their supporters (including family members) so that they can confidently use technology.
4. Review, and where necessary revise the policies and practices of those organisations that deliver education, health, and social care to ensure that they do not place unnecessary barriers in the way of enabling access to technology and effective in-home support. The experiences of those who have been providing remote support (including family members) can usefully inform this review process.

SELF-ADVOCACY GROUPS, ADVOCACY GROUPS, LEARNING DISABILITY CHARITIES, FAMILIES, DAY SERVICE PROVIDERS, TEACHERS, HEALTH, AND SOCIAL CARE PROFESSIONALS

5. Collect, curate and share examples of how supporters have used technology to support people with learning disabilities during this pandemic in order that others may be able to learn from them and adopt or adapt when they develop their own support practices. As part of this initiative, it is important that family members that have been anxious about using technology are connected to family members and other supporters who have overcome these anxieties and can share the successful strategies they have employed.
6. Set up and maintain co-operative, collaborative partnerships between those who provide in-house support (e.g. care homes, supported living; family members) and those who have the experience and expertise to provide remote support (e.g. self-advocacy groups, day services).

Finally, we argue, that in order for these recommendations to be successfully implemented it is important that all those who have a role in supporting people with learning disabilities:

7. Believe, that with the right support, people with learning disabilities have the capacity to learn to use technology. There are many examples in this report that evidence this capacity.
8. Believe that people with learning disabilities have the right to both access technology and the support to enable them to access that technology.

ACKNOWLEDGEMENTS

The research was funded by the Open University under its COVID-19 research initiative.

We would like to thank all the survey and interview respondents who were so generous with their time during a period of uncertainty and pressure for them.

We have sourced the images used in this report from two image libraries as follows:

Photosymbols: Pages 12, 16, 29, and 43.

Britannica Image Quest: Title Page, Pages 47 and 49.

In addition we wish to acknowledge the creators of the following images, obtained freely from the website UnSplash at <https://unsplash.com/>

Page 6: Photo by Tyler Lastovich on Unsplash

Page 8: Photo by William Iven on Unsplash

Page 14: Photo by Chris Montgomery on Unsplash

Page 45: Photo by Rodion Kutsaev on Unsplash



REFERENCES

- Agren, K. A., Kjellberg, A. & Hemmingson, H (2019) Digital participation? Internet Use among adolescents with and without intellectual disabilities: A comparative study. *New Media & Society*, <https://doi.org/10.1177/1461444819888398>
- Department of Health. (2007) *Valuing People Now: From Progress to Transformation*, London: HMSO.
- Gulati, G., Fistein, E., Dunne, C.P., Kelly, B.D & Murphy, V.E (2020) People with intellectual disabilities and the COVID-19 pandemic. *Irish Journal of Psychological Medicine*, May 27, 2020, 1-2. doi: 10.1017/ipm.2020.66
- Hatton, C (2020) What we know (s far) about the deaths of people with learning disabilities in England during COVIS-19. Blog post. 2nd June 2020. <https://chrishatton.blogspot.com/2020/06/what-we-know-so-far-about-deaths-of.html>
- Lodge, K-M (2020) COVID-19 shows that the lives of people with learning disability are still not treated as equal. *The BMJ Opinion*. Blog post. 1st September 2020. <https://blogs.bmj.com/bmj/2020/09/01/COVID-19-shows-that-the-lives-of-people-with-a-learning-disability-are-still-not-treated-as-equal/>
- Lussier-Desrochers, D., Normand, C. L., Romero-Torres, A., Lachapelle, Y., Godin-Tremblay, V., Dupont, M., Roux, J., Pépin-Beauchesne, L., & Bilodeau, P. (2017). Bridging the digital divide for people with intellectual disability. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, 11(1), Article 1. <https://doi.org/10.5817/CP2017-1-1>
- Rouse, L., Tilley, E., Walmsley, J., & Picken. S. (2020) Filling in the Gaps: The role of self-advocacy groups in supporting the health and well-being of people with learning disabilities throughout the pandemic. Milton Keynes, The Open University.
- Scottish Commission for Learning Disability (2020) The impact of Coronavirus on people with learning disabilities. Web page. 9th June 2020. <https://www.sclcd.org.uk/the-impact-of-coronavirus-on-people-with-learning-disabilities/>
- Seale, J., Choksi, A.J & Spencer, K (2019) I've been a whizz-kid since I've been at college: Giving voice to the collective memories of adults with learning disabilities about the role that technology has played in their lives. *Disability Studies Quarterly*, 39,4, <https://dsq-sds.org/article/view/6621/5467>
- Seale, J. (2014). The role of supporters in facilitating the use of technologies by adolescents and adults with learning disabilities: a place for positive risk-taking? *European Journal of Special Needs Education*, 29(2) pp. 220–236. DOI: <https://doi.org/10.1080/08856257.2014.906980>
- Sorbring, E., Molin, M., & Löfgren-Mårtenson, L. (2017). "I'm a mother, but I'm also a facilitator in her every-day life": Parents' voices about barriers and support for internet participation among young people with intellectual disabilities. *Cyberpsychology: Journal of Psychosocial Research on Cyberspace*, 11(1), Article 3. <https://doi.org/10.5817/CP2017-1-3>